

Book Review: A Clear-Eyed Look at the Risks of “Diagnosis Creep”

In “The Age of Diagnosis,” Suzanne O’Sullivan challenges some common assumptions about how we detect and treat disease.

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By the time neurologist Suzanne O’Sullivan met a patient she calls Darcie, the 20-year-old woman was experiencing daily seizures so disabling she had barely left her home for a year.

Darcie expected to add epilepsy to her already long list of other diagnoses: migraine, anorexia, irritable bowel syndrome, autism, depression, anxiety, attention deficit/hyperactivity disorder, a fainting and dizziness problem called postural orthostatic tachycardia syndrome, or POTS, and a joint condition called hypermobile Ehlers-Danlos syndrome.

O’Sullivan, who quickly ruled out epilepsy, came to suspect the young woman was actually suffering from another common malady: overdiagnosis.

In her new book, “[The Age of Diagnosis: How Our Obsession With Medical Labels Is Making Us Sicker](#),” O’Sullivan contends most doctors who see a large volume of patients regularly encounter young people with at least some of Darcie’s diagnoses, often in combination with Tourette’s syndrome, dyslexia and a few others. In fact, she sees an “overdiagnosis epidemic,” in which patients receive medical diagnoses that are technically correct but do not necessarily benefit them.

“I am constantly shocked that so many people in their twenties and thirties could have accrued so many disease labels at such a young age,” writes O’Sullivan, who practices in London’s National Health Services. “Older people too. Hypertension, high cholesterol, low-back pain and so on. It is becoming unusual for me to meet a patient who does not have a trail of prior diagnoses.”

Steep increases in diagnoses of cancer, dementia, chronic Lyme disease, and many other conditions may indicate that people are less mentally and physically healthy than in the past. Or perhaps physicians are better at recognizing medical problems, leading to treatment that improves their health.

O’Sullivan’s book explores another possibility: Are normal differences among individuals being diagnosed as medical conditions? By plopping modern medicine on the exam table, O’Sullivan

offers a thought-provoking challenge to our common assumptions about the importance of early and accurate diagnosis. Among them, can test results be trusted as facts? Is early intervention the best way to deal with a medical problem? And fundamentally, is having a diagnosis always better than not?

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“The Age of Diagnosis” reads like an update to [“Overdiagnosed: Making People Sick in the Pursuit of Health,”](#) a 2011 book by internist H. Gilbert Welch and two colleagues that presented compelling evidence that common conditions — hypertension, diabetes, osteoporosis and several types of cancer — are routinely overdiagnosed.

Welch lays the blame on overdetected — screening programs, imaging scans, and genetic tests that detect abnormalities that would never progress to be problems — and O’Sullivan agrees. In her view, some responsibility lies with doctors and scientists who are seduced by technological advances that allow them to spot potential problems.

But she seems more interested in the role of patients — and parents of patients — who demand a diagnosis when life does not proceed the way they want. “An expectation of constant good health, success and a smooth transition through life is met by disappointment when it doesn’t work out that way,” she writes. “Medical explanations have become the sticking plaster we use to help us manage that disappointment.”

Do other doctors share her concern? O’Sullivan’s thesis — overdiagnosis is causing harm — would be bolstered if her book included other medical voices. She instead focuses on interviews with patients, many of whom took comfort in their diagnoses, although O’Sullivan worries that they might be overdiagnoses.

She extends her critique to conditions that used to be rare or even non-existent, but are now commonly diagnosed. In recent decades, these conditions have been redefined to include a wider range of symptoms, courtesy of something she calls “diagnosis creep.”

“This occurs when the dividing line between normal and abnormal slowly shifts, so that over time, people who would once have been considered healthy are drawn into the disease group,” O’Sullivan writes.

For example, ADHD first appeared in the Diagnostic and Statistical Manual of Mental Disorders in 1968, described as distractibility and restlessness in young children. Several DSM iterations later, [ADHD](#) can now be applied to people of any age and with a wide range of symptoms and severity. As of 2018, nearly [10 percent](#) of U.S. children had been diagnosed with ADHD, according to government surveys of parents, compared with fewer than 6 percent two decades earlier. But the Centers for Disease Control and Prevention says that, for a number of different reasons, it is impossible to tell whether the increase reflects an actual change in the number of children with ADHD or simply a change in the number who were diagnosed.

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Similarly, [autism](#) has become increasingly prevalent; [1 in 31](#) American children had the diagnosis in 2022, up from 1 in 150 in 2000. Some specialists think the rising rates of autism accurately reflect the true scope of the condition, while others are skeptical — but there is no way to know for sure because there is no blood test or scan that confirms autism. “The diagnosis depends entirely on a societal agreement on what normal behavior should look like,” O’Sullivan writes.

O’Sullivan does not doubt that ADHD and autism are real conditions, but questions whether they are subject to overdiagnosis. Young children and those who are severely affected by these conditions benefit from treatment, but for older people and those with milder symptoms, O’Sullivan finds “considerably less evidence” that interventions work.

“This is the biggest marker of overdiagnosis — much higher rates of detection of diseases but no substantial improvement in long-term health,” she writes.

By contrast, she questions whether some relatively new physical disorders should even be considered diseases at all. One condition she points to is hypermobile Ehlers-Danlos syndrome, or hEDS, in which a person’s joints have an unusually large range of movement. It is one of 13 subtypes of Ehlers-Danlos syndrome; the other 12 subtypes cause biochemical changes in connective tissue, have a known genetic cause, are rare, and can be severe. Since hEDS was identified as a mild form of Ehlers-Danlos syndrome in 1997, it has become the most common form of the disorder, despite no proven pathology or genetic cause.

But hypermobile joints are common — one study estimates up to 30 percent of healthy people in their late teens and mid-20s have them — so O’Sullivan considers the diagnosis to be subjective. “The biggest difference between a healthy person with naturally hypermobile joints and somebody diagnosed with hEDS,” she writes, “is that the latter probably experienced joint pain and went to a doctor for advice.”

One danger of overdiagnosis is that it can lead to agonizing treatments that patients do not need. She cites one [study](#) that suggests a 30 percent overdiagnosis rate of breast cancer in women over age 70. “That means unnecessary mastectomies, radiotherapy and chemotherapy,” she writes.

An expert in psychosomatic illness (her 2016 book “[Is It All in Your Head?](#)” won a prize from the

Royal Society of Biology), O'Sullivan is particularly concerned about the dangers of overdiagnosis in individuals who experience real physical symptoms for psychological reasons. "Now that we have a disorder label for almost every sort of physical variation and all levels of mental anguish, I fear that people who express their emotional distress as physical symptoms can all too easily have them conflated with disease," she writes.

One of those patients is Darcie. Admitted to the hospital under O'Sullivan's care, the young woman experienced convulsions, fainting spells, and dizziness so severe that she required the help of two people if she got out of bed. But monitors that measured her brainwaves, heart rate, blood pressure, and oxygen levels showed no biological cause for her suffering.

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O'Sullivan determined that Darcie was suffering psychosomatic seizures and faints, very real but not caused by a physical problem. That made her question some of Darcie's other diagnoses. Reviewing the young woman's history, O'Sullivan speculates her "hypermobility" joints were within the normal range and that the school difficulties that led to her autism and ADHD diagnoses might have been caused from many medical absences. She believes Darcie, who first saw a specialist for headache at age 13, fell into "a trap of medicalization."

"The more she was asked about symptoms, the more she looked for them," O'Sullivan writes. "In seeking explanations, she received labels in return. All that did was heighten her health anxiety until she was so overwhelmed that she developed convulsions."

Darcie rejected O'Sullivan's thoughts about her other diagnoses, pointing out that a neurologist should stick to neurology. Nonetheless, O'Sullivan uses her case as Exhibit A for her argument that we should wonder why so many people have multiple seemingly unrelated diagnoses, many of which are uncertain in origin.

Ordinary experiences, imperfections, sadness and anxieties are increasingly given the imprimatur of medical disorders, she concludes: "In other words: we are not getting sicker — we are attributing more to sickness."

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